

*Alabama's Listening!*  
UNIVERSAL NEWBORN HEARING SCREENING

---

## Alabama Early Hearing Detection and Intervention (EHDI) Program

Leanna Rambo, BSN, RN  
Newborn Screening Nurse Educator  
Alabama Department of Public Health




### Objectives

- Describe the purpose of the Alabama EHDI Program
- Describe the Joint Committee on Infant Hearing (JCIH) 1-3-6 Guidelines
- Discuss the process for inpatient and outpatient hearing screens
- Identify the purpose of Early Intervention (EI) and the role it plays with hearing loss
- List three learning communities and two family based organizations
- Describe the role of the care coordinator in the EHDI Program

### Alabama Newborn Screening Program



Blood Spot Screen



Hearing Screen



Pulse Ox Screen



### Alabama Newborn Screening Program

Currently test for 31 primary disorders

- Sickle Cell Disease
- Cystic Fibrosis
- Endocrine Disorders
  - Congenital Hypothyroidism
  - Congenital Adrenal Hyperplasia
- Metabolic Disorders
  - Amino Acid Disorders
  - Fatty Acid Disorders
  - Organic Acid Disorders
- Severe Combined Immunodeficiency (SCID)
- Hearing Loss
- Critical Congenital Heart Disease (CCHD)




### Hearing Loss Facts

- One to three of every 1,000 infants are born with some degree of hearing loss
- Hearing loss can affect language, speech, and social skills
- Early identification and intervention is key

### What is EHDI?

- Originally enacted by Congress in 2000, the Early Hearing Detection and Intervention (EHDI) Act provides funding for early hearing and detection programs nationwide

### Early Hearing Detection and Intervention

- The goal of EHDI is to “maximize linguistic competence and literacy development for children who are deaf or hard-of-hearing”
- Can be accomplished by meeting the goals outlined in the 1-3-6 plan

### Alabama EHDI Mission Statement

- All babies born in Alabama will receive a hearing screen and results tracked to ensure early identification, treatment, and intervention of infants with hearing loss.



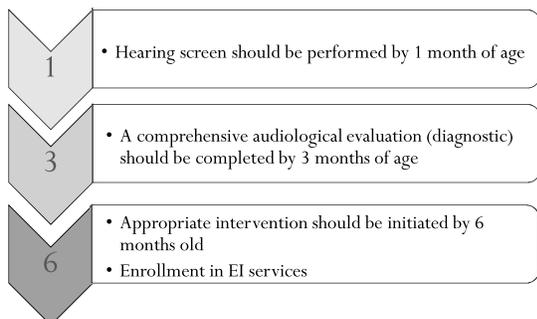
### History of Newborn Hearing Screening

- 2000 – Congress first authorized the EHDI programs
- 2001 – Alabama Department of Public Health established Universal Newborn Hearing Screening (UNHS) within the Newborn Screening Program
  - Hospitals began voluntary hearing screening
- 2008 – UNHS became mandated as part of newborn screening in Alabama

### Alabama’s Newborn Hearing Screening

- Alabama’s EHDI Program today
  - 100% grant funded
    - Health Resources and Services Administration (HRSA)
    - Centers for the Disease Control (CDC) and Prevention
  - Follows established guidelines and best practices
    - JCIH 1-3-6
    - American Speech-Language-Hearing Association (ASHA)
    - Type, Degree, and Configuration of Hearing Loss

### Joint Committee on Infant Hearing (JCIH)



### Hearing Screen

- Every infant should receive a hearing screen prior to hospital discharge
- An infant should receive no more than two inpatient hearing screens
- An infant who does not pass the hospital hearing screen should be referred for another screen before one month of age with an audiologist
- Both ears should be tested each time

### Alabama EHDI Program

- 100% Automated Auditory Brainstem Response (AABR) screening capability
- 96% of hospitals upload hearing results electronically
  - Links directly to newborn blood spot record
  - Reduces errors in reporting
  - Increases timeliness of follow-up testing and intervention

### Alabama EHDI Program

- Recent developments within EHDI program
  - Hearing Advisory Work Group
    - Multidisciplinary group convened to create a more efficient and cohesive EHDI system that meets quarterly
  - Learning Communities
    - Currently have 3 areas: Mobile, Birmingham, Huntsville
    - Would like to have more

### Family Based Organizations

- Alabama Hands & Voices is a parent-led, parent-driven, non-profit organization supporting families with children who are deaf and hard-of-hearing regardless of communication choice.



### Family Based Organizations

- Alabama Institute for Deaf and Blind Limitless Beginnings is a grant funded program to support families of deaf and hard-of-hearing children between the ages of birth and three years old, identified through the newborn hearing screening.



### Children's Rehabilitation Services (CRS)

- CRS is a statewide organization of skilled professionals providing quality medical, rehabilitative, coordination and educational support services for children with special health care needs and their families. Every county in Alabama is served through a network of 14 community-based offices.
- CRS is also providing family support services through parent consultants.



### National Center for Hearing Assessment and Management (NCHAM)

- Serves as the National Technical Resource Center for the implementation and improvement of comprehensive and effective EHDI systems
- Goal is to ensure that infants and toddlers with hearing loss are identified as early as possible and provided with timely and appropriate audiological, educational, and medical intervention



### Early Hearing Detection and Intervention – Pediatric Audiology Links to Services (EHDi-PALS)

- Information, resources, and services for children with hearing loss
- National web-based directory of facilities that offer pediatric audiology services to young children



### Hospital Recommendations

- Initial hearing screen at 12 to 18 hours of age
- Maximum of 2 inpatient hearing screens
- Upload hearing results **every** day that a hearing screen is done
- Screen **both** ears at the same time, each time
- Schedule outpatient testing prior to discharge, when needed, and notify parents of date, time, and place of appointment
- “Referral Physician” listed on blood spot form should be the medical provider who will care for infant after discharge
- Parents who refuse hearing screens should be educated on importance of infant hearing and sign refusal form

### Newborn Screening Refusal Form

**NEWBORN SCREENING REFUSAL FORM**

The American Academy of Pediatrics and the Alabama Department of Public Health strongly recommend newborn hearing screening. Parents have the right to refuse newborn hearing screening. Parents should understand that refusal to have the screening may delay or prevent early identification of hearing loss and may affect the child's educational and social outcomes.

Child's Name: \_\_\_\_\_ Date of Birth: \_\_\_\_\_ Name of Pediatrician: \_\_\_\_\_

Parent/Guardian Signature: \_\_\_\_\_

My child's medical provider has advised me that my child should avoid participation in the newborn screening program. As the parent or legal guardian of my child (named above), I choose to decline participation in my state's newborn hearing screening program. I understand that each state's criteria for its hearing screen which practices are shared by the Center for Disease Control (CDC).

I choose not to have my child receive the newborn hearing screening from the Alabama Department of Public Health in the following circumstances described by the Newborn Screening Program:

I choose not to have my child screened for hearing loss.

I understand that my child is screened for critical congenital heart disease. There have been reports of children with congenital heart disease who did not have their condition identified until after the newborn hearing screening. I have the opportunity to discuss this with my child's medical provider, who has consented my position regarding the newborn hearing screening, and explained the following:

- The purpose and need for newborn screening to include congenital hearing, hearing screening, and genetic carrier screening.
- If my child does not participate in newborn screening, the consequences of a late diagnosis may include delayed identification, educational disability, or death.
- An EHDi medical provider, the Alabama Department of Public Health, and the American Academy of Pediatrics strongly recommend that all newborns be screened for certain conditions.
- If my child has one of the specific screened conditions, there is participation in newborn screening may enhance the health of my child.

Newborn(s) I have decided at this time to decline participation in the newborn screening program for my child are indicated by checking the box above.

I understand that I have read the statement or it has been read to me in its entirety, and I fully understand it. Parent/Guardian Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Witness: \_\_\_\_\_ Date: \_\_\_\_\_

I had the opportunity to discuss my decision not to participate in my state's newborn screening program and still decline the recommended participation.

### Health Provider Recommendations

- At infant's first visit, review hearing results
- If no hearing results received, call hospital
- If no results are available from the hospital or if infant referred on the hospital screen, order a hearing screen AABR with an audiologist within the first month of infant's life
- Report results to the Alabama Newborn Hearing Screening Program

### Audiologist Recommendations

- Complete outpatient hearing screens by 1 month of age
- Schedule diagnostic testing, when needed, by 3 months of age
- Refer infants with hearing loss to EI as soon as possible and by 6 months of age
- Educate families regarding hearing loss diagnosis and importance of EI, when applicable
- Report all screening and diagnostic results via fax using the form provided by the Alabama EHDi Program

### Outpatient Reporting Forms

The image shows two sample outpatient reporting forms. The left form is titled 'HEARING SCREENING REPORT' and includes fields for patient name, date of birth, and screening results (Pass, Refer, or No Result). It also has a section for 'HEARING LOSS RECOMMENDATIONS' with checkboxes for 'Hearing Loss', 'Hearing Loss with Risk Factors', and 'Hearing Loss with Significant Risk Factors'. The right form is titled 'HEARING LOSS RECOMMENDATION REPORT' and includes fields for patient name, date of birth, and screening results. It also has a section for 'HEARING LOSS RECOMMENDATIONS' with checkboxes for 'Hearing Loss', 'Hearing Loss with Risk Factors', and 'Hearing Loss with Significant Risk Factors'. Both forms include a section for 'HEARING LOSS RECOMMENDATIONS' with checkboxes for 'Hearing Loss', 'Hearing Loss with Risk Factors', and 'Hearing Loss with Significant Risk Factors'.

### Care Coordinator Role

#### Two types of care coordination:

- Medicaid
- Non-Medicaid

### Care Coordinator Role

#### Support Families by:

- Transportation
- Communication with doctor
- Links to insurance programs
- Emotional support
- Resources for other issues identified
- Home visits as needed

### Care Coordinator Role

- The Care Coordinator (CC) may follow up with the hospital to verify final hearing screen result
- CC should ensure appropriate testing completed

### Care Coordinator Role

- CC should educate physician and family, providing needed assistance, to ensure appropriate follow up care is completed
- Diagnosis – Normal hearing or Hearing Loss?
- Report confirmed diagnosis (type and severity of hearing loss)

### Care Coordinator Role

- An infant with confirmed hearing loss, should be referred to EI by 6 months of age or sooner if a diagnosis is made
  - Educate family on EI referral and benefits of enrollment (provide Pathways to Families if needed)
- Provide all contact information to EHDI program for DHR follow up when an infant is placed in foster care

### Pathways for Families Resource Book

- This book was developed to assist professionals and parents as they make decisions related to appropriate services and supports. It includes an in depth list of organizations and websites.



### Care Coordination Recommendations

- Ensure all scheduled appointments follow JCIH timeline
  - 1 Outpatient hearing screen by one month of age
  - 3 Diagnostic evaluation by 3 months of age
  - 6 Enrollment in EI by 6 months of age

### Reporting Results

- Provide accurate and complete information
  - Ensure the *birth* name is included
  - Verify the date of birth is correct
  - Provide the most up-to-date contact information for the family
- Accurate and complete information helps to ensure timely and efficient identification and intervention
- Follow Care Coordinator’s Protocol

### Risk Factors for Hearing Loss

- Family history of permanent childhood hearing loss
- NICU stay of more than 5 days
- Exposure to ototoxic medications or loop diuretics
- Exposure to certain infections, such as cytomegalovirus (CMV) or meningitis
- Craniofacial anomalies
- Head trauma
- Chemotherapy

### American Speech-Language-Hearing Association

- Types of Hearing Loss
  - Conductive hearing loss
  - Sensorineural hearing loss
  - Mixed

**AT BIOLOGY** Information Series **Type, Degree, and Configuration of Hearing Loss**



### American Speech-Language-Hearing Association

- Degree of Hearing Loss
  - Seven classifications ranging from normal to profound

Degree of hearing loss	Hearing loss range (dB HL)
Normal	-10 to 15
Slight	16 to 25
Mild	26 to 40
Moderate	41 to 55
Moderately severe	56 to 70
Severe	71 to 90
Profound	91+

Source: Clark, J. G. (1981). Uses and abuses of hearing loss classification. *Audio*, 23, 493-506.



### American Speech-Language-Hearing Association

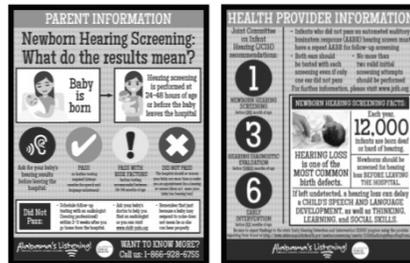
- Configuration of Hearing Loss
  - Defines degree and pattern of hearing loss across different frequencies



### Alabama EHDI Program Role

- Gather and correlate data
- Manage and coordinate with providers on those who refer initial screen
- Nurse Coordinator works directly with Non-Medicaid and Medicaid Care Coordinators to obtain hearing results
- Educate on JCIH 1-3-6
- Refer all hearing loss infants to EI services
- Manage website to provide families and providers with up to date information

### Parent and Health Provider Information



Order brochures for parents online at:  
<https://www.adph.org/Extranet/Forms/Form.asp?formID=7935>

### For More Information

- [aidb.org](http://aidb.org)
- [alabamapublichealth.gov/newbornscreening](http://alabamapublichealth.gov/newbornscreening)
- [alhandsandvoices.org](http://alhandsandvoices.org)
- [asha.org](http://asha.org)
- [ehdi-pals.org](http://ehdi-pals.org)
- [infanthearing.org](http://infanthearing.org)
- [jcih.org](http://jcih.org)
- [rehab.alabama.gov/services/crs](http://rehab.alabama.gov/services/crs)

### Contact Information

- Contact the Alabama Newborn Screening Program at 1-866-928-6755
- Mary Ellen Whigham, RN, Alabama EHDI Coordinator, Nurse Supervisor  
[mary.whigham@adph.state.al.us](mailto:mary.whigham@adph.state.al.us)
- Nancy Strong, RN, BSN, Alabama EHDI Surveillance Nurse Coordinator  
[nancy.strong@adph.state.al.us](mailto:nancy.strong@adph.state.al.us)

SUMMER MACIAS

A New Mother's Journey

MARIA KATZ

A Parent's Journey

## NEWBORN HEARING CARE COORDINATION PROTOCOL

Carolyn Miller, LICSW, PIP

## NEWBORN HEARING PROTOCOL

Summary of Revised Protocol:

- Includes new attachments:
  - Newborn Screening Reference manual for Providers, Section 3 – Newborn Hearing Screening
  - Letter in Document Library (Letter to Medical Providers)
- Stresses the 1 – 3 – 6 guidelines.

## NEWBORN HEARING PROTOCOL

- The role of the new FHS Social Worker dedicated to Newborn Hearing.
- List of determinations for Care Coordinators upon receipt of referral.
- Updated information if parents refuse testing.
- Resources to Parents/Families.
- How to address a delayed newborn hearing test.

## NEWBORN SCREENING REFERENCE MANUAL FOR PROVIDERS

- Located in Appendix A and mentioned in the Goal of Newborn Hearing Care Coordination
- Flow Chart for Newborn Hearing Screenings based on Joint Committee on Infant Hearing (JCIH) Guidelines
- Guidelines for Pediatric Providers
- CRS and EHDI information

## DEFINITIONS

- Emphasis on the difference between OAE and ABR testing:
  - OAE is preferred method of testing for babies at least six months old
  - ABR is the preferred method of testing for all newborns up to six months old, and especially premature infants admitted to the NICU.
  - Child Find phone number is included in the Early Intervention definition to make an EI referral for babies identified with hearing loss.

## FHS SOCIAL WORKER

- Angela Daniel was hired as the FHS Social Work Sr. to provide care coordination services to all non-Medicaid hearing referrals. Responsibilities include:
  - Verifying Medicaid on all referrals
  - Sending out referrals through CCRS

### FHS SOCIAL WORKER

- Provide care coordination services to non-Medicaid newborn hearing referrals.
- If a home visit is required, the referral may be sent to the District.
- If the newborn receives Medicaid, Angela will send the referral to the appropriate District.
- If a newborn referred to the District loses Medicaid benefits, the District Social Worker will email Angela and transfer the case back to her.

### RECEIPT OF REFERRAL

Upon receipt of referral, the CC should determine:

- Was a subsequent rescreen already performed after the infant did not pass the initial hospital screening?
- What was the method of testing?
- Was the infant admitted to the NICU greater than 5 days?
- Were both ears tested?
- Are there any risk factors known for delayed or late-onset hearing loss?

### REFUSAL OF TESTING

- Parents may refuse testing based on religious tenets and practices.
- Notify the Newborn Screening Program if parents refuse testing.
- Newborn Screening Staff will refer them to the baby's doctor for education/counseling on the importance of screening.

### DELAYED HEARING TEST

- Providers sometime delay the hearing test due to middle ear effusion or fluid in the ears (not recommended).
- American Academy of Pediatrics has indicated this should not delay a hearing diagnosis since it has the potential to further compromise hearing.
- Notify the Newborn Screening Program if testing is delayed so that they may send the Best Practice Letter to the baby's doctor. (Appendix C)

### CARE COORDINATION REMINDERS

- Know the difference between the types of newborn hearing screenings (AABR and OAE) and be proactive for the newborn.
- 1 – 3 – 6 is our goal! Keep to strict timelines to verify appointments were kept and reschedule quickly.

### CARE COORDINATION REMINDERS

- Don't close cases too soon. Keep cases open until necessary screenings and evaluations are complete, and the newborn is in appropriate treatment.
- For medical providers who will not provide needed information, send them the Standard Letter – HIPAA and Newborn Screening 11/09/2020 found in Document Library under Compliance and Ethics.

## CONTACT INFORMATION

Angela Daniel, LBSW

[Angela.Daniel@adph.state.al.us](mailto:Angela.Daniel@adph.state.al.us)

334-206-2942

Dianne Chandler, LMSW

[Dianne.Chandler@adph.state.al.us](mailto:Dianne.Chandler@adph.state.al.us)

334-206-9435

Carolyn Miller, LICSW, PIP

[Carolyn.Miller@adph.state.al.us](mailto:Carolyn.Miller@adph.state.al.us)

334-206-2959

